

Understanding the Value of Volunteers in Hospice and Palliative Care: Language Matters



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Opinion

Volunteers provide direct patient care in many palliative care settings in collaboration with care of professionals and family [1,2]. Framing their contribution as differential from professional care and family care has value for further development of volunteer practices. How can the essence of direct patient care volunteering be clarified? Several studies point at 'being there' as an appropriate frame, referring to theories on presence and presencing originating from nursing studies, management studies, and from care ethical and theological theories [3]. Core descriptions of presence in healthcare contain: totally being with, seeking for relational attunement, unconditional love for the vulnerable other [4].

Since the conceptual description of presence in palliative care seems to contrast with language used in many palliative care studies we explored letters of volunteers themselves. We read 100 letters of Dutch volunteers, written by 13 men and 87 women with a specific interest in discourse used and framing of care activities [5]. It became clear that volunteers focus at being successful in creating attunement with the care receivers, volunteers focus at increasing their receptivity and open mindedness. For instance by actively diminishing thoughts related to their own daily lives.

Judy (HPC volunteer): What is important in this work? To open yourself for the other and put your worries aside. To stay at the background, but alert. To listen well. Not wanting too much, but to act complementarily. Not judging.

Volunteers describe that this means stepping back from the acting modus and to still the thinking, by restraining from distractedness and opinions. What one volunteer experiences as holding back, is described by another one as emptying herself. Volunteers express that they invest in creating inner space and receptiveness for the care receiver and family members.

Claire (age 47, volunteer in home situation): At the same time I started as a palliative care volunteer. There I learnt that once I am with a patient as a volunteer, I go back to 'silencing'. It is a kind of meditation. I am there and that is

most important. I can be there full of attention for the other. All beautiful conversations, incidents, extra's, maybe are the cream on top of the cake. The cake is being given to connect with the other within a safe and trustful surrounding.

Volunteers non-verbally create a space in which the patient can express him- or herself. They are focused at sensing who the other is and what might help him or her. By reading the other before words are used, they can adapt to the patient.

Martha (age 73, HPC volunteer): What I found a miraculous experience, something I had no idea about when I started, is the first acquaintance with a new hospice guest. I had developed the habit to stay on the doorstep for a while, after knocking and opening the door of the room. I then felt the atmosphere and adapted my attitude.

'Being there' appears to be a practice that asks a lot more than being in the room physically. According to the letters of volunteers, it is experienced as holding oneself back, being silent, offering space, increasing attentiveness. Based on this, a volunteer 'reads' who the other is, what is at stake and what her best response could be.

Maria (age 55, HPC volunteer): The 'being there' for our guests and their family is a recurrent aspect in which one can develop oneself. Due to the experiences with different guests you learn again every time how to act or not to act. We are at the background and observe. We say something or nothing. We guide people to the other side in their rhythm and way of doing. Every human being is unique, every dying is unique, and we are privileged to be present. It is special that upon dying, every person returns to her of his own self. With all the lessons learnt. We as volunteers can make this last road as comfortable as possible, or at least try to.

All is aimed at the possibility of offering social connection. Connection through very small or very large things, that help the other to prevent isolation. The way they look and listen is part of the quality of their volunteer work. Being sensitive to the concerns and emotions of the other is key in this work.

June (age 59, hospice volunteer): How does one react to the feelings that come to the surface in changing mix with the patient and their family? Astonishment, denial, protest, depression and acceptance. You do not know beforehand in which phase someone 'finds oneself'. We sometimes do not know anymore. Still, one does have to radiate the trust and quietness to accept that there is no way back.

The analysis shows that attunement comes first and making a difference in such a situation is 'hidden' in tiny daily things. By becoming excellent relationship builders, volunteers read the situation and find what these can be.

Carla (age 48, HPC volunteer): You don't have to talk all the time, silence says so much more than words. And those are mainly small things, that you can give people a good feeling for the day or that moment. It can be the odor of coffee, a flower with breakfast, a bowl with fruit presented nicely or a smile. Humor also helps a lot. It can break the ice with people who prefer to stay in control and continue with that.

Being able to make a difference happens if relational bridges can be built to the dying people and offering presence at meaningful moments in the lives.

Judith (age 62, HPC volunteer): A very beautiful situation was that a lady had her 70th birthday and that nobody wanted to go there because "it was something burdened". What can one say? Do you congratulate her? What else can you say? I was glad that I could go there. I must tell you it was a party. The lady called me early in the morning, I went down. Before I could say anything she told me she was looking forward to have breakfast together with me and that we were going to celebrate her birthday. She had not been able to sit at the table for a while, always lying in bed. Now she wanted to sit on the table. She was making the table for me. It was a very special moment in my life. It was about 25 years ago, but I can still see it as if it happened today.

For a successful being there a relational 'click' is necessary. Only the patients and family members can evaluate if that relational connection was experienced.

Anna (age 61, HPC volunteer): What makes this work valuable is when an old man or lady takes your hand and says: "thank you for everything", that is the core: Being there. If you are able to spend five weeks with a man with whom it clicks. When he is able to tell his life story again, about which the daughters says: "Yes, dad, we heard that story already ten years ago, let's talk about something else." We have all the time to hear that story and maybe he wants to express something else with that story. In five weeks a beautiful connection grows with the patient as well as with the family. Often beautiful conversations take place, very valuable.

The letters show that acknowledging what makes a person unique, has value in this palliative phase. This understanding of

who the other is and what is needed at the existential level is the heart of volunteering. Volunteers search for ways to help to patient to surrender at this level, to attain peace.

Carlo (age 70, HPC volunteer) I was thirteen weeks with a man who in the beginning asked to switch on the TV and watch the stocks and I asked him, are you in the mood? After some weeks it was more about questions of life, it became more confidential. He sometimes told things he did not plan to share. It did give him rest.

In short, volunteers create a cocoon of attention and unconditional love around the patient in which he or she may transform towards death. In this transition existential loneliness may appear since no one can join the patient. If and how this is experienced is quite hard to find out, while it is difficult as well to know what will help. Being there then means: trying to find out what is experienced by the other and becoming with the other needs.

Jane (age 59, HPC volunteer): And then comes the next stage: her path to death, what makes her dreary and dejected. I sit with her and ask why she feels so down and maybe depressive. She answers that she feels so lonely and explains that she is not scared for death. But the road is so lonely that she can share it with no one, since nobody can confirm that experience and recall it afterwards. Everyone is empathic and near, but no one knows what it really means to walk such a path! It moved me and I thanked her for her openness.

These citations illustrate that framing the contribution of volunteers as tasks or roles is often not sensitive enough to the compassionate relational processes that volunteers consider the heart of their work. Several aspects of volunteering practices, among which collaboration with professionals might benefit from in depth knowledge of presence theories as a base to further clarify, evaluate and improve volunteers' contributions to palliative care.

References

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